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ABSTRACT

One clinical psychologist worked with terminally ill, end-stage Acquired Immune Deficiency Syndrome (AIDS) patients in a hospice type setting for an 18-month time period. Interventions included individual psychotherapy, mental status assessments, staff group sessions, and supportive services for families and significant others. During that time, 285 patients were seen, of whom 175 have since died. The suffering of AIDS patients can be compared to that of prisoners in Nazi concentration camps during World War II, and the need for the therapist to deal with such widespread suffering can be compared to dealing with combat during that war. In beginning to work with AIDS patients, the psychologist had to deal with his own homophobia and prejudices, to be himself at all times and not appear too intimidating or threatening to new patients. In order to structure therapy sessions around the needs and wants of the clients, any traditional psychological approaches and techniques had to be abandoned in favor of an effort to catch the patients at those precise times when they were willing to be seen. In spite of what the therapist learned about working with AIDS patients through experience, there remain many unanswered questions and much unfinished work. (NB)

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"The Creative Use Of Psychotherapy With Terminally Ill Persons With Aids"

by

William A. Fraenkel

Presented at 98th AnnualConvention

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at

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William A. Fraenkel

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

My presentation will highlight some aspects of my most recent experiences over an 18 month time period where I work in a hospice type nursing care facility in northern New Jersey three days a week as a clinical psychologist with terminally illl, end-stage persons diagnosed as having Aids. My activities include individual psychotherapy, mental status assessments, staff group sessions and supportive services for families, friends, loved ones and caring significant others. During this time period I have seen some 285 persons of which number 175 have since died. I was present with a number of these persons as their deaths approached. In several instances I was there as they died. I participated with staff when some of their bodies were being wrapped and marked and then placed in body bags to be sent to the funeral parlor for burial.

Never before have I ever experienced or witnessed such immense sadness or deep sorrow nor really understood the awesomeness of such excrutciating pain felt by so many human beings which was balanced somewhat by observing how bravely some of these persons handled their daily afflictions and continuous grief as they held on to their lives and persevered. It was at some of these moments that I had vivid flashbacks of my former World War II combat Marine infantryman experiences when I participated in three major battles, "D Day" landings and became involved in numerous killings, deaths and faced my own fragile mortality and yet managed to still survive imminent death.

While my work of necessity enables me to share in the daily lives and experiences and frustrations and upsets of many different persons with terminal Aids as they try to deal with their deaths and dying, I witness human disfigurements beyond description, young gaunt bodies wasting away, ribs showing through emaciated chests, skull bone features protruding from twisted human figures, spindly weak legs, thinner than the person's wrists, skeletal shapes somehow still alive and able to walk slowly about hesitantly or painfully as others edge their wheelchairs down a hallway or elsewhere as I hear persons screaming out from their rooms in endless convulsed pain, and then I come to feel the deep anguish and the immense suffering that prevails and overpowers.

The days pass and I still manage to go on with my work though I am often upset or depressed or sad or angry or anxious. Somehow I get through each day and reconfirm my commitment to life, my need to continue my unfinished work and through thoughts of my caring wife, my children, grandchild and significant others, manage to gather the necessary strength I need to continue on. Oftentimes what helps me through such difficult and stressful and depressing daily experiences is the strength I am able to gather from many of the people I am with as I witness them defying death and dying in all of its forms, struggling to somehow keep themselves alive, beyond their expected, allotted times, demonstrating the human quality of survival, the will to live, if only for a brief additional moment more, holding on to life tenaciously, seemingly, by a fragile, single golden thread.

These events often call to my mind the renouned work and experiences of Viktor Frankl, especially his vivid descriptions of survival in Nazi concentration camps during World War II and through his theory of personality as reflected by his Logotherapy wherein a person's spiritual values are called upon to assist to enable them to find more meaning to their dreary, disillusioned,depressive lives allowing some of them to take on more responsibility for themselves and the situations they find themselves in, and come to know their unique significance.

To begin with, I found it necessary to first acknowledge and then try to deal with some of those homophobic feelings and negative attitudes and prejudices I held towards gays and junkies, IVDA's, prostitutes, criminals and bisexuals. These categories of persons constituted the majority of those I was to see and try to help. I also had to understand and accept and respond to many people with vastly different ecomomic, political, social, personal, educational and ethnic value systems and lifestyles. This is not to say that everyone I saw was in such classifications for there were a few college graduates, ministers, middle-management persons, artisans, retired businessmen as well as a dentist and a physician.

At the start, it was agreed upon by my boss and the administrator of the facility that it was important that I dress properly and wear a shirt, tie and jacket when on duty. However I still found many a door closed to me or persons heavily invested in card games or other activities they felt might have insulated them

from seeing me. Others were quick to feign sleep or suddenly became engrossed in some type activity as I approached. The message I received loud and clear was 'Keep Out". or "Stay Away', or "Don't Disturb'. A few were right up front and in a loud resonant voice for everyone else's benefit would tell me, 'Fuck Off'.

Secondly, I found it crucial to always be myself and not appear too intimidating or threatening to newly arrived residents who I always manage to see the first day they arrive, once they are settled in their rooms. I try to come on low-keyed, relaxed and as casual and informal as I can be. I usually first offer my hand in friendship or in some other way make sure physical contact is made. I try to be sensitive to their feelings and responses to my presence, letting them sense my full acceptance of them as they are. Most of my initial contacts are very brief but in the process I let them know I'm available, care about them and am there to help them make the most of their stay.

Thirdly, I became accustomed to not expect to conduct formalized meetings with persons on a regularly scheduled basis as though I were seeing persons in my private practice. This never happened. Nor did I ever find giving any standardized test meaningful. I used the Weschler Memort Scale, Mini Mental Status Exam, The Bender and Figure Drawings, once in a while. No test takes more than ten minutes to administer. Any psychotherapeutic session lasting more than one half hour usually resulted in the person becoming very fatigued or restless or disinterested or nodding off. I could never get four persons together for 30 minutes to hear a

meditative tape or experience a guided visualization session no matter how well we planned such meetings. This transpired even when requests for these sessions came from seemingly well motivated and highly interested persons. What generally occured was that the session scheduled a few days before was subsequently forgotten or one of the group was so fatigued he/she couldn't get it together to leave bed to dress and appear at the session. Another person might have had a very bad night before with unexpected night sweats or chills or spiked a temp or had diarrhea or felt too sick to attend. Someone else might have had to be rehospitalized for an emergency transfusion or one might have had a sudden downturn of health and then died unexpectedly. We never had success with these occasions.

I discovered early on that I needed to discard most of my traditional psychological approaches, techniques and methods. I found it very usefulto try to find ways to enter their daily lives without being intrusive; to try to catch them at those precise moments or minutes when they appeared ready to see me. This meant I would usually see some persons as many as eight to ten times a week with each encounter lasting but a few brief minutes. I also saw the value of coming to the facility by 6AM to give input at the 7AM nursing staff changeover from the night shift to the day shift.

I feel that I was most productive and successful when I was per-

ceived as a valued, caring, concerned person who they felt they could trust and rely on to say whatever was on their mind, at any time, even though we all knew that what was expressed might never result in resolution or meaningful change in their daily lives. Their need to ventilate and my need to carefully listen was paramount. My love and respect and caring for them was openly acknowledged to my constant embarrasment. I also believe that I had probably broken ever barrier to countertransference and no doubt had violated every rule and standard on it. Even so, no one ever crossed the line with each of us maintaining the appropiate

respect and distance needed to continue the relationship.

As I end my remarks, my thoughts and feelings return to my unfinished work. I think about how I will respond to the many young men and women and others in their prime as they face their mortality. I wonder how I will react when someone calls me over to ask why the bed rails are raised or wants to know why they have to be in a geriatric chair or wheelchair or require someone to now supervise their smoking a cigarette or watch as they struggle to open a small milk container and then require help to sip out of a straw or ask me why no one comes to visit them any more or let them know they are still valued even though they wear diapers,and then I panic when (someone) stares into my eyes asking,"Why me,Doc? Why me?" "Why do I have to die of Aids?" as tears well up in my eyes.